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**Editorial**

*Ian Gale and Simon Gibbs*

Inclusion remains a slowly developing process - more problematic in some areas and with regard to some children. This issue of *Educational and Child Psychology*, focussing on children with severe, complex and enduring needs, coincides with a significant anniversary in the UK. 40 years ago, prior to 1970, most of these young people, particularly those with severe or profound intellectual impairments, would, in the UK at least, have been considered “ineducable”, excluded completely from the education system and attending Junior Training Centres (JTCs) rather than schools. The first paper in this issue of the Journal, by MacKay, outlines much of the history of issues related to definition, terminology and prevalence. He illustrates how complex and confusing the field may be and how some children and young people may, quite literally, be located at the statistical margins of education. Much of that marginalisation (some might say segregation) remains despite changes in many other aspects of educational policy and practice. When JTCs became schools for children with severe learning difficulties specialist training courses for teachers were set up and extensive work followed in an attempt to establish suitable curricula and teaching methods. Some of this drew on philosophical developments in adult services (e.g. normalisation (Wolfensberger, 1972) the Kings Fund paper “An Ordinary Life” (1980) and O’Brien’s “Five Accomplishments” (1987)) to establish inclusion in community settings and paid work as long term goals.

Paradoxically, in Britain the National Curriculum, intended in principle to meet the needs of all children, had the effect of derailing several potentially positive curriculum developments within special schools. Despite the possibility of “individually tailored” curricula, the National Curriculum became the benchmark for assessing all schools, leaving many children at “Working toward Level 1” for the totality of their school careers. One of the editors, asking an advisor from the Department for Education and Science what had been intended to happen, was told at the time that the DfES “hadn’t really known what to suggest for these children and had hoped we might tell them”. This curriculum deficit was recognised after some 10 years by the introduction of the “P scales”. Nevertheless for teachers who intend to

work with these children, whether in special schools and/or in mainstream settings, specialist training is still hard to find and they often start this work with only a cursory knowledge of the curriculum required and how it might be delivered.

To contextualise this, Male and Rayner provide some measure of the demands on staff in special schools in England for children “with severe learning difficulties” at the present time. They suggest the characteristics of the children educated in these schools are changing and that many continue to present significant challenges - in terms of their learning and behaviour - that ‘mainstream’ schools often feel unqualified to meet. Male and Rayner also suggest that despite an increasingly diverse pupil population in special schools there is a decrease in the proportion of staff with additional qualifications, leading some Headteachers to express concerns about the recruitment and retention of appropriately qualified staff in the future.

As Lindsay (2007) pointed out, mainstream inclusion is currently very much a values based choice as we know comparatively little about the parameters and moderators for what works. We hope the papers published in this issue of Educational and Child Psychology will promote discussion of issues relevant to applied psychologists and others working in this field. Whilst the number of children in this sector is small relative to the overall school population, this low incidence does not reflect the magnitude of the impact that the difficulties experienced by some children can have on their families, carers, educators and services in general. Too often, in our experience, families and services, lacking appropriate knowledge, support or resources, are unable to cope with these difficulties. Children are then often placed outside their local community in expensive specialist provision, often counter to the preferences of their families.

In his account of work with parents and carers, Gale provides vivid illustrations of the impact that severe and complex needs can have on them, and how, faced by exceptional behaviour, previous descriptions of ‘locus of control’ may become unsustainable. Likewise, Hames and Rollings describe the feelings of loneliness, guilt and lack of confidence in their parenting skills that parents may report but how support for them and the sharing of experience can bring not only comfort but lead to improvements in the behaviour of their children. Mercieca and Mercieca detail

another and intriguing form of support for parents by helping them use multi-sensory approaches to develop their children's literacy.

In work with adults who present with complex needs and sometimes Challenging Behaviour<sup>1</sup> there is a well established evidence base for the effectiveness of approaches based on Applied Behavioural Analysis, and the papers here by Grindle and her associates and by Adams & Dunsmuir demonstrate the current use of such approaches in both teaching new skills and responding to more difficult behaviours in children with autism spectrum disorders.

There is always the danger that we find ourselves pathologising children with severe and complex impairments and in so doing furthering their exclusion and segregation. The paper by Chasouris and colleagues reminds us to be cautious even when extrapolating to the likely outcomes of a well-defined condition such as William's syndrome, particularly when this is based on limited data.

The views and experiences of young people themselves should be both valued and influential. For inclusion to be meaningful, no young person should be marginalised nor treated as a passive recipient of services prescribed by others with no long term personal investment in the consequences of placement or provision. Harding's paper is a timely reminder of how one might enable this group of children to make their views and experiences known so that due account can be taken of these.

The exceptional needs of the children discussed in these papers test the boundaries of our philosophy, psychology and practice, exposing the gaps in our knowledge, understanding and skill. We suggest some of those gaps (and the questions they raise) include:

1. The lack of evidence on current outcomes and best practice for including this group of children (see Lindsay, op.cit.). Parents of children with complex needs maintained in mainstream, for example, often complain that their children effectively "train" staff each year before moving to the care of new staff, while successful inclusion in mainstream appears to be reliant on a skill

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<sup>1</sup> See papers by Gale and Male & Rayner for definitions of Challenging Behaviour.

base currently maintained by special schools. However, as Male & Rayner indicate, even that skill base may be at risk. How might relevant knowledge and skills be extended and best deployed across all sectors and phases of education and children's lives?

2. In relation to recent initiatives Arksey et al (2007) note that although the 'Every Child Matters' policy (DfES, 2004) emphasises children's safety and well-being, the substantial care-related needs of children and the risks for parents' and family well-being that can arise from the presence of severe childhood impairment are largely overlooked (unlike similar guidance for care of the elderly). How can services become more 'joined up' and effective in meeting these needs?
3. Similarly, the P scales, although they provide a more appropriate basis for planning and monitoring progress in school, do not address skills such as using the toilet which may be important both for future inclusion and for human dignity. Looking at this more broadly, could a curriculum for life be developed? If so what might be included in an appropriate secondary age curriculum for a young person still functioning within the P scales? The Routes for Learning materials developed by the Welsh Assembly Qualification and Curriculum Group (2006) may represent one way to approach to these questions.
4. The social model of disability is widely accepted by most practitioners in the field of severe and complex intellectual impairments. However, as Shakespeare & Watson (2002) note in a wider critique of the "strong" model of social disability, the impact of impairment and being 'disabled' may not be defined solely by either a medical condition or by social barriers, and this is especially so for children with the most severe and complex needs. How should a social constructionist approach be balanced against avoiding the potential danger arising from ignorance of condition-specific risks (such as the increased risk of self injury in children with Cornelia de Lange syndrome (Moss et al, 2005) or the increased risk of being bullied for children with specific speech and language problems (Knox & Conti-Ramsden, 2007)) ?
5. The increased risk of out of area placement for the children with the most challenging behaviours has been referred to above. ABA practitioners such as La Vigna and Willis (e.g. LaVigna & Willis 2005) emphasise their belief that

it should be possible to maintain all children and young people (and adults) with complex needs and challenging behaviours within local community provision using only positive means, provided that necessary distinctions are made between immediate reactive programmes (to contain and reduce the severity of the most dangerous behaviours) and longer term positive programmes to develop appropriate skills in both students and caregivers. Can we develop such programmes with both families and providers that are socially, economically, ethically and morally valid and acceptable?

6. Finally, how far should we aim for mainstream inclusion for all children with such complex needs? And in considering this question should we see inclusion as an end in itself or primarily as a means to achieving outcomes such as the “Five Accomplishments” and better quality of life in adulthood for those with severe and complex needs?

All these issues, and others, need greater debate and a better comparative evidence base than is currently available. Hattie (2005) noted that almost all interventions introduced to schools (i.e. deliberate attempts to change, improve, plan modify or innovate) show a positive effect, with an average effect size of about 0.4. This suggests that improvement alone is insufficient to identify best practice (we may just be seeing the equivalent of placebo). An additional complication with respect to challenging behaviour is that what is effective may not be socially (or in some cases ethically) acceptable. If we are to take another step forward as big as that taken 40 years ago and make significant improvements in desirable and inclusive social and educational outcomes for children with severe and complex impairments, then we need you, our readers, to engage in active debate of these and other issues and to seek out comparative evidence (both qualitative and quantitative) for different approaches so we can identify what works, what doesn't and what other questions we need to ask and be asked as we develop provision for this highly vulnerable group of children.

## References

Arksey, H., Beresford, B., Glendinning, C., Greco, V. & Sloper, T (2007) *Outcomes for parents with disabled children and carers of disabled or older adults:*

- Similarities, differences and the implications for assessment practice* Yor: Socila Policy Research Unit, University of York
- Department for Education and Science (2004) *Every Child Matters: Change for Children* Nottingham: DfES Publications
- Hattie, J. (2005) The paradox of reducing class size and improving learning outcomes *International Journal of Educational Research* 43, 387–425
- LaVigna, G.W. & Willis, T.J. (2005) A Positive Behavioural Support Model for Breaking the Barriers to Social and Community Inclusion *Tizard Learning Disability Review*, 10(2), 16-23
- Lindsay, G. (2007) Educational psychology and the effectiveness of inclusive education/mainstreaming. *British Journal of Educational Psychology*, 77(1), 1-24
- The King's Fund (1980) *An ordinary life: comprehensive locally-based residential services for mentally handicapped people* London: King's Fund Centre
- Knox, E. & Conti-Ramsden, G. (2007) Bullying in young people with a history of specific language impairment (SLI). *Educational and Child Psychology*, 24, 130-141
- Moss, J., Oliver, C., Hall, S., Arron, A., Sloneem, J. & Petty, J. (2005) The association between environmental events and self-injurious behaviour in Cornelia de Lange syndrome *Journal of Intellectual Disability Research*, 49(4) 269-277
- O'Brien, J. (1987). A guide to lifestyle planning. In B. Wilcox and T. Bellamy, eds. *A comprehensive guide to the activities catalog*. Baltimore: Paul Brookes Publishing
- Shakespeare, T. & Watson, N. (2002. ) The social model of disability: an outdated ideology? *Research in Social Science and Disability*, 2, 9–28
- Welsh Assembly Qualification and Curriculum Group (2006) *Routes for Learning* available at <http://old.accac.org.uk/eng/content.php?cID=3&pID=1309>
- Wolfensberger, W. (1972). *The principle of Normalization in human services*. Toronto: National Institute on Mental Retardation